

## How the Shift to Individualize Supports Gets Stuck and The First Step Out of Gridlock

Hanns Meissner

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Many mature and successful service providers continue to find their identity in the heritage of moving people with developmental disabilities out of public institutions. Significant achievements such as providing residential alternatives to large facilities do not immune providers from criticism emerging from a growing demand for individualized supports. The Individualized Supports Think Tank, a group of self-advocates, parents, and service providers convened by the Self-Advocacy Association of New York State (2007) expressed this demand:

We define individualized supports as an array of supports, services and resources that are person-centered, based on the unique interests and needs of the person, afford the person as much control over their supports as they desire, and are adaptable as the person's life changes. This means that supports are created around an individual's distinct vision for their [sic] life rather than created around a facility or funding stream.

From this perspective, some would claim that the most dominant forms of accomplishments of the era of deinstitutionalization look like mini-institutions that offer few and constricted options. These options tend to consign people to full time clienthood, where they are excessively controlled by caregivers and are prevented from fully participating in community life. As the full responsibility for the quality of people's lives continues to be delegated to service providers by families, communities, and generic services, the growing demand for long-term supports challenges the sustainability of developmental disability systems.

The argument that typical service providers are caught in a pattern of "strengths becoming weaknesses" in the face of shifting service expectations becomes more salient as sophisticated service systems experience great difficulty in implementing individualized supports. There have been modifications in language and procedure—most everything has been labeled as "person-centered" for more than a

decade—but the investments of state systems and the efforts of most service providers remain centered in programs designed to place and manage people with developmental disabilities in suitable groups. Facilities and funding streams continue to dominate despite policy commitments to individualization. Frustration and the temptation to cynicism grow as advocates experience little movement toward what they understand as individualized services. Service providers continue to report little demand for change ("Our consumers and their families are highly satisfied with current services") and complain of a thicket of fiscal and regulatory obstacles that entangle their steps toward individualization. Policy changes, strategic plan objectives, exhortation, training courses, and financial incentives have not shifted the prevailing pattern. The move toward individualized services is stuck.

The roots of this gridlock lie in beliefs and assumptions about people with developmental disabilities that are embodied in and reinforced by the culture of the service system. The individualization that growing numbers of people with developmental disabilities and their families and allies call for is not superficial and transactional, but deep and transformational. It is not a matter of dispassionately working on redesigning structures, independent of the relationships, practices, emotions, and mental models of the managers, professionals, families, and people with developmental disabilities creating the change. It is a matter of opening up space for innovation in a culture that includes those who want to make room for new arrangements by surfacing their assumptions about what is possible for people with intellectual disability both in terms of their capacity for an inclusive life and options to support new outcomes.

One good move when stuck is to find a way to describe the mental models in play. This process begins with engaging in a dialog about the various beliefs and assumptions that shape perception of

people with developmental disabilities themselves, as the following example of contrasting mental models illustrates. If we see people with developmental disabilities as fundamentally vulnerable and incapable, the role of service providers is to take care, protect, and decide for people and the role of service systems is to create rules, incentives, and mechanisms of inspection and enforcement that assure safety and adequate care. On the other hand, if we see people with developmental disabilities as capable of contributing meaningfully to community life, the service provider is one partner in discovering and offering the individualized supports, interest-based opportunities, and safeguards that enhance participation, satisfaction, and resilience. The service system holds responsibility for investing public funds that are sufficient and flexible to sustain individualized supports, developing an adequate supply of capable and ethical service providers, and offering an additional level of safeguards to people's autonomy and community membership.

These distinct mental models justify profoundly different service systems and shape almost incommensurable understandings of key ideas like person-centered work and individualized services. Trying to simply overlay structures and practices intended to offer individualized support for community contribution on a system shaped by beliefs that persons with intellectual disability are exclusively vulnerable and incompetent will get mired in more of the same. So will change strategies based on the notion that shifting paradigms of understanding is as simple as jumping from one state to another on command. What is necessary is the kind of purposeful listening relationships that encourage awareness and suspension of the assumptions and beliefs that reinforce gridlock and the exploration of an understanding more aligned with the purpose of developing individualized supports. Such relationships become a springboard for prototyping new ways to partner and provide supports that can form and flourish if there is a supporting environment (Scharmer, 2009; Mount & VanEck, in press).

Not only do mental models shape our sense of what is desirable and possible for people with developmental disabilities, we also are strongly influenced by the way we make sense of change. Some understand *change* as the straightforward replacement of one way of doing things by another better one. Given this definition of change,

adopting individualized services is like replacing one's mobile phone with a smartphone. The old is discarded; the new adopted. Change is a matter of marketing a new product by convincing people that the gain outweighs the pain of change or that the cost of resisting the command to change is higher than the cost of changing. A more powerful image views the field of developmental disabilities services as being like a natural ecosystem, with many different life forms existing and evolving simultaneously. Some are dying out as their niche shrinks, others mobilize most of the available resources as they pass through their adaptive peak, still others are experiments of life that make the most of capacities unused by the dominant forms or released by what is dying.

Table 1 sketches a map of the developmental disabilities ecosystem that offers people who want to develop individualized services a way to locate their efforts and consider the multiple dimensions of necessary change. It identifies a succession of four different forms of service, all of which are currently sharing the field.

Though the legitimacy of institutional care is declining and its sustainability is in grave doubt, the transfer of institutional structures, practices, and assumptions into many local service settings makes it still the dominant form. Managed care is also strong and, in most places, integrative supports and community supports are just emerging at the innovative edges of the field.

Institutional care is system-centered, with provider organizations and state systems delegated full responsibility for meeting every officially defined need in service models for diagnostic groups and plans for individuals designed and directed by professional experts. People with disabilities and their families are passive clients. The system is hierarchical and operates through command and control, reflecting the dynamics of power-over relationships. Its infrastructure is founded on legal requirements that are specified and monitored in detail with a strong aversion to any potential risk. These requirements and the compliance sensibility that pervades institutional care arise in reaction to the abuse and neglect that people with developmental disabilities are vulnerable to and the possibilities for real or perceived misuse of public funds. Decision-makers are sensitized to deficiencies in people with developmental disabilities, service providers, and ordinary citizens. The system manages very high levels of detail

**Table 1** Evolution of Developmental Disabilities Services

Organizing citizen-centered principle	System-centered	Outcome-centered	Person-centered	Citizen-centered
Individual resource-professional relationship	Expert-patient (professional direction)	Provider-consumer (professional responding)	Facilitator-broker (professional facilitating)	Resource-autonomous-citizen (professional-ancillary)
Service-individual interface	Functionally specified services and models Model-driven (pull)	Habilitation pathways (core process) Service-driven (push)	Wrap-around Supports person-driven (negotiated)	In-home and community located supports Community-driven (allocated)
Innovation mechanism	Administrative and functional effectiveness and efficiencies internal to the system Make standardized service models	Outcome-driven, cross-functional, inter-organizational Deliver customized services	Person-centered interorganizational State and co-create personalized experiences	Citizen-centered community-based Support individual citizen autonomy
Dominant type of complexity	Many details to manage	Complex interaction between environmental factors	Complex interaction between key stakeholders	Unclear and emerging futures
Coordination mechanism	Hierarchy and command	Market price	Network, dialogue, and mutual adaptation	Seeing from the whole community
Infrastructure	Social legislation (laws, regulations, budget)	Rules, norms to make the market place work	Infrastructure for learning and innovation	Infrastructure for seeing in the context of the whole
Primary outcomes and emergent outcomes for individuals	Placement, personal care activity, and housing	Face to face services, residential living community presence	Individualized supports leading to jobs, home, and relationship	Citizenship and valued roles

complexity in assuring compliance in order to deliver placement in day service settings and group residences, personal care, and activity.

Managed care is outcome-centered and designed to provide the system with the means to control costs by implementing cost-effective pathways to habilitative results. Framed by a waiver from some institutional requirements negotiated between state and federal Medicaid agencies, the system becomes a sort of marketplace, with multiple providers seeking

contracts with the state system and referrals from a service coordination system charged with making and monitoring Individual Service Plans (ISPs) that reflect people's needs for support. People with developmental disabilities and their families are often seen as customers to be satisfied by the offerings and efforts of service providers. Though they are often called consumers, people or their guardians do not have control of funds. Money is allocated through a complex political bureaucratic process of rate setting

that, along with regulation and inspection, are the primary means to coordinating and managing the system. Service providers often work hard to influence the norms and practices that govern their marketplace. There is potential flexibility to respond to individual difference, but provider organizations and state systems remain the holders of delegated responsibility to assure compliance with regulations intended to keep people healthy, safe, and moving toward agreed goals. The system allocates many of its costs through billable units of face-to-face contacts, so, in a sense, such contact is an outcome of managed care avidly tracked by service providers. A generation of small group residences and day programs that support people's presence in community settings have come into being with managed care funding, though innovation is typically the design and implementation of a revised program model rather than arrangements tailored to individual circumstances.

Institutional care and managed care display considerable continuity, but a major shift separates them from the innovative edges of the field: integrative supports and community supports. These two pairs of approaches to support are as different from each other as a manual typewriter and a new laptop in terms of function, design, capacity, and mode of production.

Integrative supports and community supports both require a re-ordering of relationships with and around people who have developmental disabilities and their family. These relationships are based on a fundamental shift to power with a committed group of people with differing assets. They bring to the task of supporting people with developmental disabilities the pulling together of many assets necessary to have a flourishing life. Mindful effort to discover and build on a sense of the person's developing capacities and autonomy guides the work, which is rooted in the values of democracy and the struggle by people with disabilities for human and civil rights and recognition that continuing learning and innovation are essential. The need for competent assistance and a variety of safeguards is negotiated on a person-by-person, situation-by-situation through deliberation rather than assigned to simple conformity with external rules. Individuals with developmental disabilities and their family do not delegate complete responsibility to service providers. They build security and flexibility by extending and organizing their personal networks, taking as much control of system resources as circumstances allow, and

maintaining dialog that allows continuing mutual adjustment with the people they rely on for assistance. Service providers act as suppliers of trustworthy assistants, brokers, facilitators, and partners in innovative ventures. They stretch themselves to include more and more people with complex needs and difficult circumstances. The state system's role is to assure fair and adequate funds for necessary assistance, actively promote learning and innovation, and safeguard those people and families who are isolated and vulnerable until they can find the connections they require.

These innovative forms of support differ primarily in their horizon of action. Integrative supports are focused on the proximate desires of more and more people with developmental disabilities to live a real life. When people with developmental disabilities have the experience of others listening to them respectfully, living a real life means having a place to call home, an intimate relationship, friends, and a real job. In the current service ecology, achieving these ordinary human desires calls for a great deal of skillful partnership in innovation and negotiation to mobilize disability system funds and build productive connections with other local assets, such as housing providers and employers.

Community supports assist people to hold even wider aspirations than living a real life. Service workers develop their capacities to act as a resource to people's exploration of their contributions as citizens to building stronger neighborhoods, associations, congregations, and a more inclusive and sustainable local economy, polity, and environment. Innovation focuses on supporting people to take up valued and contributing social roles in a greater variety of settings.

These shifts may reflect yet another evolution of how we view persons with developmental disabilities and their place in our world. This, in turn, has an impact on how the system and providers of service respond to this emerging social dynamic. How to encourage the emergence of new service paradigms without engaging in a never-ending dance of competing commitments is the core question for those who seek an inclusive life for persons with intellectual disability. Teasing out and nurturing evolutionary thinking and doing is the task for transformational leaders in all sectors of our society (i.e., in families, in our neighborhoods and governmental sectors, and in business and nonprofit arenas). Promoting cultural change (i.e.,

shifting mental model) requires innovation that is socially focused. This is about innovating generative relationships, not discovering new technology. Social innovation calls for actions that ignite personal journeys of self-awareness, realigning relationships away from hierarchy to partnership, and transforming our communities where difference and diversity is embraced. Although social innovation can take place within any sector, more than likely it will occur in the white spaces between the family, local community, business, nonprofit providers and government. When we learn to move from our defined spaces and roles into a common community agenda, perhaps individualized supports will then become mainstream practice.

A cultural change that supports persons with disabilities to assume full citizenship in our local communities and experience a real life requires the morphing of deeply held beliefs about disability and the roles and relationships at all levels (individual, team, organization, state, and nation) and sectors of society (household, civic, government, profit, and nonprofit) from “taking care of” to partnership with people who have disabilities. As mental models shift, a capacity to see the world from a different perspective is developed. From new perspectives, new relationships among individuals, organizations, and sectors in society are formed to create social innovations that ignite movement towards a more progressive support model. Ultimately, cultural change emerges from the ongoing interaction and social negotiation that occurs among key community members during processes that enable innovative support practices.

Committed change leaders with a vision of citizenship leading to lives of valued contribution and involvement for persons with intellectual disabilities can start the change process with an

invitation to engagement. The invitation goes out to all key stakeholders to join in a journey of self and system transformation. From a place of profound appreciation and humility, safe social clearings and containers for dialogic inquiry, deep learning, and innovative practice are created and nurtured. In doing this we are reordering our world away from fragmentation and delegation to community connections. There will be a need for new power arrangements and organizational forms. Critical to this transformational process is finding added the leverage points for change by working within our present service structures, redesigning traditional services to individualized supports, and/or inventing new ways to support individuals with intellectual disability as true citizens of our communities.

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## Author:

**Hanns Meissner, PhD** (e-mail: [HMeissner@renarc.org](mailto:HMeissner@renarc.org)), Executive Director, The Arc of Rensselaer County, 79 102nd St., Troy, NY 12180.